

February 11, 2016

RE: SB 1568 Citizen Testimony for Same-Date Hearing

I am an Oregon disabled constituent, Juli T. Star-Alexander, testifying to the Legislature on SB 1568 with my information and concerns; I appreciate the opportunity to participate in my State Government. Any comment or information to me personally may be sent to the email address to which this document is attached (chatbratstar@gmail.com). I am sorry I am not there to present this testimony in person.

I have been disabled since 1995 due to a head injury and multiple strokes incurred in a car accident in which I was not at fault. However, it was later discovered that I also suffer a genetic defect which makes my symptoms progress through to death at any time. I prefer not to name the disability due to privacy act concerns.

When the genetic defect was discovered in 2007, I resigned as Executive Director of a nationally known 501(c)3 organization set up to advocate for victims of legal abuse (of which I suffered much due to my own disability symptoms by uninformed government employees without knowledge of their lawful duties regarding the disabled). I took formal training in the advocacy of disabled individuals, received accreditation, and only stopped renewing that certification in December 2015, due to progressing symptoms. My training is the same as that which is offered to judges and lawyers for Continuing Legal Education mandated by State Bars.

SB 1568 “Prohibits discrimination based on age, expected length of life, present or predicted disability, degree of medical dependency or quality of life in determination of medical services covered by state medical assistance program, in coverage under medical retainer practice and in issuance of health benefit plans. Applies to medical retainer practices and health benefit plans in force on January 2, 2017.”

While the proviso “medical services covered by state medical assistance program”, and while my current primary insurer is Medicare and secondary is Tricare for Life (Medicare Wrap Program), my situation makes very possible that without intervention I will become a Medicaid patient for in-patient long-term care unless my concerns are addressed at this time (cost of which is estimated to be around \$250,000/year (medical condition estimate 8-10 years or more).

While finances are not my primary thrust in this testimony, it should be a concern to the State of Oregon. Disabled people are (especially those with “hidden disabilities “ which are often deemed to be suffering from personality disorders/psychological, rather than neurological or physiological -- humans have not yet evolved to the level of x-ray vision or precognition), therefore punished. Having drawn such premature conclusions, the disabled is often then invalidated and abused due to the rampant discrimination of government employees.

My concerns are as follows:

1. Doctors/Physician Assistants/Nurse Practitioners are currently allowing themselves a right to terminate a patient without stated causes, as has happened to me and a number of others in my geographical area, Oakridge/Dexter (typical for PA Edwin Weih) for whom I placed a Yelp alert. Such allowance conflicts with federal Americans with Disabilities/Amendment Acts nondiscrimination standards; whether the reality of disability symptoms is deemed too frightening or noncompliant and results in medical termination of services, medical people are front-line for understanding the working model for disabled patients. This is a discrimination which must be stopped. When a person presents as disabled and presents information proving the disability, that medical person should not allow disabled people to lose medical care/treatment. Because many health-care providers no longer take Medicare patients even with a wrap-around plan, it puts a disabled person in the position of no medical care and a need to shop for more despite the disability. It certainly engenders lack of trust or confidence in the medical community. When I moved to Oregon, I contacted dozens of providers looking for primary care because the standard (not law) is that specialists will not accept patients without referral which creates a no-win situation and abuse to the disabled.
2. People with hidden disabilities must have a chart note and health-care providers of all types must post notice in their offices to agree to work with State and Federal law regarding [such hidden] disabilities, to include things such as Central Auditory Processing Disorder or Hyperacusis. (In those cases, background noise such as television and music playing must be interrupted upon request, without argument.)
3. No patient advocates exist in Oregon (other than the Department of Justice, but they do so only from a legal standpoint and are useless unless they agree to perform litigation after investigation to the best of my knowledge) rendering those of us with cognitive damage forced to continuously engage with a medical system that places “policy” over practicality or federal law. Patient advocates are needed. Funding them would be less expensive than litigation.
4. It must be written within the confines of State Code that those of us with cognitive deficits must be allowed to record all conversations, including telephone conversations (see also federal wiretap standards and violation of ADA accommodations; no government or medical provider who is acting lawfully should be in fear that such ADA accommodation would be used against them) the purpose of which is an attempt to level a playing field of information transmission that is denied to those of us with hidden disabilities or memory impairment.

5. No medical entity should be allowed to charge a disabled patient for missed appointments when the missed appointment is due to disability symptoms. I had such an attempt made in writing against me by PeaceHealth.
6. Neuro-psychiatric training for cognitive retraining (neuroplasticity) must be encoded for availability in non-discrimination type legislation so as to help such patients regain whatever awareness they may possibly regain, unless specifically rejected by the patients. Medical care providers may suggest treatment but must never force treatment, including psychotropic or anti-psychotic medication which, unfortunately, can cause great harm to a group of people as is well known through experts. Demented patients do not benefit from feeding tubes, and nationally the experts have come out against it. This issue is especially timely as multiple resources should that there is an epidemic of dementias (whether caused by aspirin brain-bleeds, pesticides, pollutants and particulate matter, etc.).
7. The State of Oregon must stand firmly against the use of constraints against people with “hidden disabilities”; such failure to do so has caused death to numerous citizens by health care providers and police officers. Even those with hidden disabilities will calm down if given time and rest to do so.
8. It must be written within the confines of State Code that police officers must, immediately upon being informed of hidden disabilities, make provision for a neutral patient advocate be made present during all questioning, and that copies of recordings be made available to the disabled upon request, either in writing or by phone, yet maintain confidentiality under HIPAA. This relates to a negative experience I encountered in Grants Pass. I do have a letter from that police captain asking that I not include him in litigation (he failed to comprehend his unlawful complicity with his underling and had admitted to zero ADA/AA training).
9. It must be made mandatory that all government employees at all levels receive training in the Americans with Disabilities Act and Amendments Act in order to perform their government duties in compliance with federal ADAAA law. I have found no government employees thus far with any of this training although one person in the Department of Aging and Disability admitted to being in training at the time I talked to her. All government entities must include easily locatable email addresses for contact. All government entities must have ADA compliant web sites.
10. It must be addressed by the State that those disabled individuals not be denied proper levels of pain management care. While I suffer greatly from pain, I am not yet in the desire for such medical care, but know others who have become considered “drug-seeking individuals” and are then denied their medications. This issue requires assistance. Sympathetic pain reflex syndromes are rarely understood here, it seems.

11. The current status of the Death with Dignity law allows doctors to use a crystal ball method of determining when a suffering patient without hope of improvement or recovery may be allowed to obtain the prescription for lawful life-termination drugs, allowing them to avoid having to obtain such drugs illegally (such as heroin overdose). Six months, twelve months... all standards are overly burdensome and therefore useless. The government, State or Federal, has no vested interest in making the situation discriminatory by including a timeframe at all. This should be at the discretion of the patient. In fact, such timeframe actually acts against those severely disabled by creating an unconscionable burden on the disabled. Some patients may end up unable to proceed with a DwD request due to time delays in even obtaining such prescription, and some of those will end up in an Oregon paid long-term care facility against their expressed wishes, suffering extremely, and needlessly due to this overly burdensome and unnecessary constraint. Some people may only seek constitutionally protected provisions through death. We all die. None of us are very important that we should all have to suffer due to a State instituted standard. While I am one who has and freely shares an executed Advanced Medical Directive, many others do not know what it is or are unable to execute it fully.
12. Also, since Medicare and Tricare for Life do not cover home health-care nursing, such burden would be passed onto the Oregon Medicare system. It has been discovered that it is less expensive for a State to pay for in-home care than for long-term nursing care, by far. This issue should become formally codified as mandatory as optional upon first response.
13. Patients who request Death with Dignity should not have their medical treatment limited or stopped after receiving the prescription insofar as an attitude that they need to die renders them ineligible for further care.
14. Reverse age discrimination should not be allowed. In the materials on the Patients Rights Council (an organization which actually fights against euthanasia, unfortunately) it is found that an 84-year-old early dementia patient was finally allowed DwD in spite of concerns that the daughter was pushing for the death. A person with, for example, early Alzheimer's or genetic Alzheimer's (such as was portrayed in the recent movie "Still Alice") should be allowed to pass at the time of their wish and not required to live out a life of complete debility. This issue is relevant as noted in the Summary. This does apply to nondiscrimination standards affecting the fatal flaw in the DwD law which can be rectified in this Senate Bill. I am in possession of a DwD email which instructs me to withhold food and drink in order to die due to the timeframe constraint written into law. How horrific for the loved ones to watch, and how appalling the favoritism is towards a disease process other than long-term deterioration (and how bizarre to receive such a written response from a "compassionate care" organization.
15. A person with total paralysis should be assisted in death at their request, such as was portrayed in the true to life movie, "The Butterfly and the Diving Bell". This

issue is relevant as noted in the Summary. This does apply to nondiscrimination standards affecting the fatal flaw in the DwD law which can be rectified in this Senate Bill. It allows a totally paralyzed individual to live years without hope. Legal protection should exist just as it exists for the sick individuals who help those on death row to die. If not rectified, again, certain conditions are treated without dignity or compassion and reflect badly on a society which forces long-term suffering on people who have already suffered great tragedy.

16. The federal Genetic Nondiscrimination Act currently applies in employment and insurance but, in all fairness, States must include such nondiscrimination standards into medical care and DwD.

Thank you for taking the time to review my concerns.

Juli T. Star-Alexander
76504 Pine Street #1336
Oakridge, OR 97463